

2020 NPCR NEBRASKA CANCER REGISTRY SUCCESS STORY

STORY TOPIC: Early Case Capture (ECC) of Pediatric and Young Adult Cancers

STORY CATEGORY: Public Health Impact

STORY TITLE: Succeeding on So Many Different Levels

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SUMMARY

In 2008, the Caroline Price Walker Conquer Childhood Cancer Act was signed into law by Congress. The law entitled the Centers for Disease Control and Prevention (CDC) to fund the enhancement and expansion of the infrastructure to track the epidemiology of pediatric cancer into a comprehensive nationwide registry of actual occurrences of pediatric cancer.

The main objective of the Early Case Capture (ECC) for Pediatric and Young Adult Cancer Cases funding was to collect cancer data for the age group of 0-19 years of the latest available year and the cases would be reported within 30 days of initial diagnosis. The funding has been awarded twice and Nebraska was included in both awards. The ECC funding provided great opportunities and challenges simultaneously to the Nebraska Cancer Registry (NCR). The NCR successfully completed the ECC project through tremendous efforts by the NCR staff to onboard and retain the facilities, as well as provide training and ongoing education to the facility staff.

CHALLENGE

Our challenges were manifold.

1. Small hospitals, clinics and physician offices were supported by the NCR staff coming on site to abstract their data once a year. The ECC project required these smaller facilities to report their data to the NCR within 30 days of diagnosis.
2. The necessity to report within 30 days required the development of a tracking system to monitor each facility's compliance to report within that timeframe. Several facilities resisted sharing this information with some of their staff expressing that this information was really "none of the state's business".
3. The reporting facilities required a significant amount of education with repeated reinforcement and follow up with NCR team members.
4. Information Technology (IT) support for the subcontracted data collection office was limited. The NCR staff had to rely on an external vendor, the Rocky Mountain Cancer Data Systems (RMCDs), to provide the abstracting software and IT support. The NCR was administered by the Nebraska Department of Health and Human Services (DHHS) and the IT departments of the DHHS also provided additional technical support.
5. The NCR data collection staff were contracted employees through the Nebraska Methodist Hospital located in a different city as the Nebraska DHHS.
6. The eMaRC Plus electronic pathology reporting was not yet implemented. Pathology reports were either faxed or sent by USPS in paper format. Both methods required manual processing for

data collection, entry, filing, and follow-up.

SOLUTION

Funding allowed the hiring of additional staff to be trained as a CTR to coordinate the ECC data collection. The NCR created and sent the Nebraska cancer registry hospitals as well as the small hospitals, clinics and physician offices a quarterly newsletter. The newsletters served as the media to provide more data collection information such as new guidelines, rules and data requirements for individuals who needed more information or gentle reminders. Additionally, the NCR staff promoted and presented the ECC information and updates in the annual meeting of the Tumor Registrar Association of Nebraska (TRAN). The NCR utilized all possible networking opportunities to connect with other colleagues in hospital as well as state registries. Through the networking at a Rocky Mountain workshop, a contact was established with a children's hospital in Colorado that resulted in the NCR receiving case reports from that facility.

RESULTS

The NCR successfully completed the ECC project in Nebraska. NCR estimated the completeness of the cancer data for the ECC age group to be approximately 100-120 cases per year. During the ECC project period our case counts were: 2012 – 132 cases, 2013 – 128 cases, 2014 – 111 cases, 2015 – 101 cases, 2016 – 126 cases, 2017 – 133 cases, and 2018 - 101 cases. The percentage of the data collected within 30 days after the initial diagnosis and completed based on the ECC project period requirement increased from 49% in 2013 to 76% in 2018. Many of the small hospitals and clinics are still proactively sending cases or their monthly case finding list to the NCR. Due to the ECC requirement for data reporting within a short time frame, the small hospitals used their electronic health record systems (EHR) systems to securely transfer cancer data to the NCR via secure email or secure file transfer protocol. The NCR staff travel expenses were saved by no longer needing to go to each small hospital or clinic for data collection.

The ECC data collected by the NCR has been used in public health practice and research. A University of Nebraska Medical Center researcher requested the ECC data to examine the association between environmental factors and pediatric cancers. The Nebraska DHHS also used the ECC data to create pediatric cancer fact sheets to reflect the burden of pediatric cancers among Nebraska residents. The fact sheets have been published on the Nebraska DHHS NCR website. Additionally, the information has been presented at both the Nebraska Cancer Registry Task Force meeting and the Tumor Registrars Association of Nebraska (TRAN) workshop.

SUSTAINING SUCCESS

Because of the ECC success, the NCR gained valuable experience in recruiting and retaining reporting facilities. Early this year, the CDC NPCR initiated the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) project to track pediatric and young adult cancer cases (age group of 0 to 29 years). Nebraska was selected again as a pilot state. The STAR project aims to improve rapid case ascertainment of the pediatric and young adult cancer patients and strengthen electronic pathology reporting system. With the support of the CDC STAR team, the success of the ECC will be sustained and enhanced in Nebraska.

REGISTRY CONTACT INFORMATION

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